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Breast Cancer Survivors

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INTRODUCTION

Despite general consensus that breast cancer survivors should undergo annual mammography, findings indicate over 1 in 7 women fail to receive a mammogram within 2 years of breast cancer treatment, and that African Americans are almost half as likely to participate in mammography screening as Caucasians. The main objective of this study is to develop and pilot a survey instrument to understand what influences a woman's decision to receive surveillance care following treatment with curative intent for breast cancer and whether different factors are more or less important to different racially defined population subgroups. This study consists of four parts. First, initial formation from existing literature was used to identify factors that influence a breast cancer survivor's decision to participate in mammography screening. Second, to ensure the cultural and other appropriateness of the survey instrument developed, four focus groups were conducted: two among Caucasian breast cancer survivors and two among African American breast cancer survivors. Results from these focus groups and the literature were used to develop a mailed survey to elicit breast cancer survivors' beliefs, social influences, and preferences regarding mammography screening programs. In the third phase, pilot testing the survey instrument was conducted using a random sample of African American and Caucasian breast cancer survivors. In the fourth and final phase, among the pilot sample, we described patient beliefs, social influences, and preferences for program attributes regarding mammography participation by race and explored the relationship of these patient-level factors to mammography participation.

BODY

Human Subjects Protection Approval

Initial project-related efforts were focused on obtaining the necessary approvals for the use of human subjects, both from Henry Ford Health System's (HFHS) Human Rights Committee, Institutional Review Board (IRB), and the Human Subjects Research Review Board (HSRRB) within the Department of the Army. Upon contract initiation (i.e., July 2001), approval was in place for the use of human subjects from the HFHS's Human Rights Committee. Notification of approval of the use of human subjects was received from the Department of the Army's HSRRB on February 27, 2002.

Study Cohort Identification

Efforts during the first project year also included those necessary to identify the study cohort. The target population of our research was women aged 40 years or older who have survived breast cancer and were eligible to receive follow-up or post-treatment mammography surveillance care. To identify these women, we used the data available within the HFHS' Corporate Data Store, which is a mainframe data repository. Data from an electronic cancer registry was used to identify women who were diagnosed with in situ or regional breast cancer between 1/1/95 through 12/31/00. This list of patients was limited to those over the age of 40 who received treatment with curative intent and was stratified by mammogram use in the first 18 months following diagnosis. Information regarding treatment with curative intent and mammogram use was obtained from electronic claims databases. The resulting cohort (N=2052) served as the sampling frame for both the focus group and survey research efforts.

Focus Group Research Recruitment

A random sub-sample of eligible cohort members (N=543) was selected for focus group participation. Once this sample was identified, the corresponding physicians were

contacted via letter to obtain permission to contact their patients. For those sample members for whom physician permission to contact was obtained (N=525), a letter of study introduction was mailed to each potential participant. These letters were followed by a personal telephone call from a project team member, requesting that the woman participate in a focus group. At the time of the call, each potential participant was asked a series of questions to ensure that she met the study eligibility criteria and also to place her in one of four focus groups, which were distinguished by ethnicity and utilization of mammogram screening following breast cancer treatment with curative intent. In order to meet our proposed goal of obtaining six to eight participants per group, we recruited twelve persons for each group; the average attendance rate was ultimately 7 persons per group. A detailed summary of our overall recruitment process is provided in Appendix B.

Survey Research Recruitment

The remaining eligible sample (i.e., those who did not participate in the focus groups) was selected for mailed survey administration. Again, the patients' principal physicians were contacted via letter to notify them of intent to contact their patients. For those sample members for whom physician permission to contact was obtained (N=674), a survey instrument was mailed to each eligible sample member. With the approval of the Human Subjects Protection Board and the HFHS' IRB, the original protocol for survey administration was amended to become one that was anonymous. Surveys were color-coded to reflect a participant's mammogram utilization in the prior year. The survey packets included a letter of study introduction, survey instrument, and self-addressed and stamped return envelopes. The returned surveys were scanned into a database via Teleform (a scannable form processing software program). Overall, 256 surveys were returned.

Literature Review Results

During the first project year, we completed a comprehensive literature review to identify both conceptual models of health care utilization and specific factors previously found to be associated with mammography use. Results from the literature review led to the development of a conceptual model of mammography use among breast cancer survivors. This model, which is depicted in Appendix C, draws heavily upon both the health behavior and economic literature¹⁻⁸, and reflects our theorized importance of not only patient beliefs, social influences, and physician relationship factors, but also patient preferences for different mammography screening program attributes such as the accuracy of the test, the privacy of the results, and the pain associated with testing.

Focus Group Results

Each of the focus groups were facilitated by experienced leaders from SPEC Associates, a consulting and management company. The facilitators were selected to ensure that their ethnicity matched that of the focus group participants. Prior to the focus group sessions, the facilitators were provided written focus group guidelines and overall goals of the discussion (see Appendix D). For each session, two individuals of concordant race per focus group served as scribes. Each session was also audiotaped. Appendix E summarizes the focus group discussion findings.

Survey Research Results

Using the conceptual model we developed and the information obtained from the focus groups, a mailed survey was designed to cover the range of factors that may influence a breast cancer survivor's decision to undergo mammography receipt following treatment with curative intent. The survey (see Appendix F) was designed to cover five main types of factors:

background characteristics, such as health status and socio-demographics; individual beliefs regarding disease susceptibility and curability; social influences; physician relationships, interactions, and trust; and preferences for different screening attributes.

Chi-square tests and Wilcoxon rank sum tests were performed to examine differences between African Americans and Caucasians as well as those identified in the electronic claims database as having had a mammogram within 18 months following treatment with curative intent (“users”) and those who were not identified as such (“non-users”).

The results tables for analyses by race are in Appendix G. Some key research findings include:

- A significantly higher percentage of Caucasian women than African American women considered accuracy of the mammogram to be one of the most important attributes of the exam (65% vs. 47%, respectively, $p<.05$).
- A significantly higher percentage of African American women than Caucasian women considered pain/discomfort to be one of the most important attributes of the exam (27% vs. 13%, respectively, $p<.05$).
- Significantly more African American women than Caucasian women considered the inclusion of similar ethnic background of clinic staff to be important (36% vs. 10%, respectively, $p<.01$).
- A significantly greater percentage of African Americans have concerns about the privacy of the information that is exchanged with their physician.
- Fewer African Americans feel they are involved in decisions about their medical care as much as they want than Caucasians (84% vs. 96%, respectively, $p<.01$).

- Considerable consensus around the attributes reported as important when deciding whether or not to use mammography screening. Regardless of race, breast cancer survivors rated test accuracy, speed of result availability, and pain and discomfort as “very important.”

For the comparisons of the “user” (i.e., one who had a record of mammogram use in the first 18 months following diagnosis of breast cancer) vs. “non-user” groups, appropriate analyses were not able to be performed due to the disproportionate low response rate the non-user group. The results tables for analyses by race are in Appendix H. Some notable findings and trends include:

- A significantly greater proportion of the user group compared to the non-user group ranked receipt of reminder notices for appointments as “important” or “very important” to mammogram utilization (85% vs. 57%, $p < .001$).
- A greater percentage of users versus non-users ranked respect of privacy as one of the most important attributes to mammogram utilization.
- A greater percentage of user versus non-users ranked ease of appointment to fit into schedule as one of the most important attributes to mammogram utilization.
- A significantly greater proportion of users reported receiving understandable answers from their physicians during an office visit more often than non-users.

KEY RESEARCH ACCOMPLISHMENTS

- Conducted comprehensive literature review to identify factors that influence a breast cancer survivor's decision to participate in mammography screening. This review included identification of specific factors as well as conceptual models of health behavior.
- Developed a theoretical model of mammography use upon which to design the pilot survey. This model encompasses patient beliefs, social influences, physician relationship factors, and patient preferences for different mammography screening program attributes.
- Identified a cohort of 2052 breast cancer survivors who met the study eligibility criteria. These women constituted the sampling frame for both the focus group and survey research efforts.
- Conducted four focus groups to identify the factors breast cancer survivors consider when deciding whether or not to have a mammogram and to inform the final development of the survey instrument.
- Prepared detailed summaries of focus group discussions and resulting themes.
- Developed and administered mailed survey. Survey was designed to describe breast cancer survivors' beliefs, social influences, and preferences regarding mammography screening programs.
- Performed statistical analyses examining differences between Caucasian and African American breast cancer survivors' perspectives of breast cancer screening as well as potential differences between those identified in the electronic claims database as having had a mammogram following treatment with curative intent and those who had not.

REPORTABLE OUTCOMES

- Conceptual model of mammography use developed (Appendix C). This model has been adapted for use to evaluate colorectal cancer screening decisions among a general population and used in a proposed submission to the National Cancer Institute.
- Poster presented to the Era of Hope 2002 Department of Defense Breast Cancer Research Program Meeting, entitled, "Understanding Racial Disparities in Mammography Use among Breast Cancer Survivors." Please see Appendix I.
- Abstract submitted to Society for Medical Decision Making regarding the racial differences in the stated importance of mammography screening features after treatment for breast cancer (Appendix J).

CONCLUSIONS

Efforts under this developmental award have been quite productive and informative. These efforts resulted in the formation of a conceptual model of mammography use and the development of a mailed survey to understand the factors associated with the decision to undergo mammography surveillance among racially diverse populations. Although survey response rates among non-users precluded us from evaluating racial differences in the factors associated with mammogram use following breast cancer treatment, the results provide promising preliminary data for subsequent efforts. We are currently formulating ideas to continue investigations into understanding the mammography use decision making process and whether this process differs by race. A primary consideration in the subsequent efforts will be how to improve research participation rates among non-users.

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Appendix A:

Personnel

APPENDIX A

Personnel on Project

Jennifer Elston Lafata, PhD - Principal Investigator

Bruce McCarthy, MD, MPH - Co-Investigator

Marvella Ford, PhD - Co-Investigator

Katherine Harris, PhD - Co-Investigator

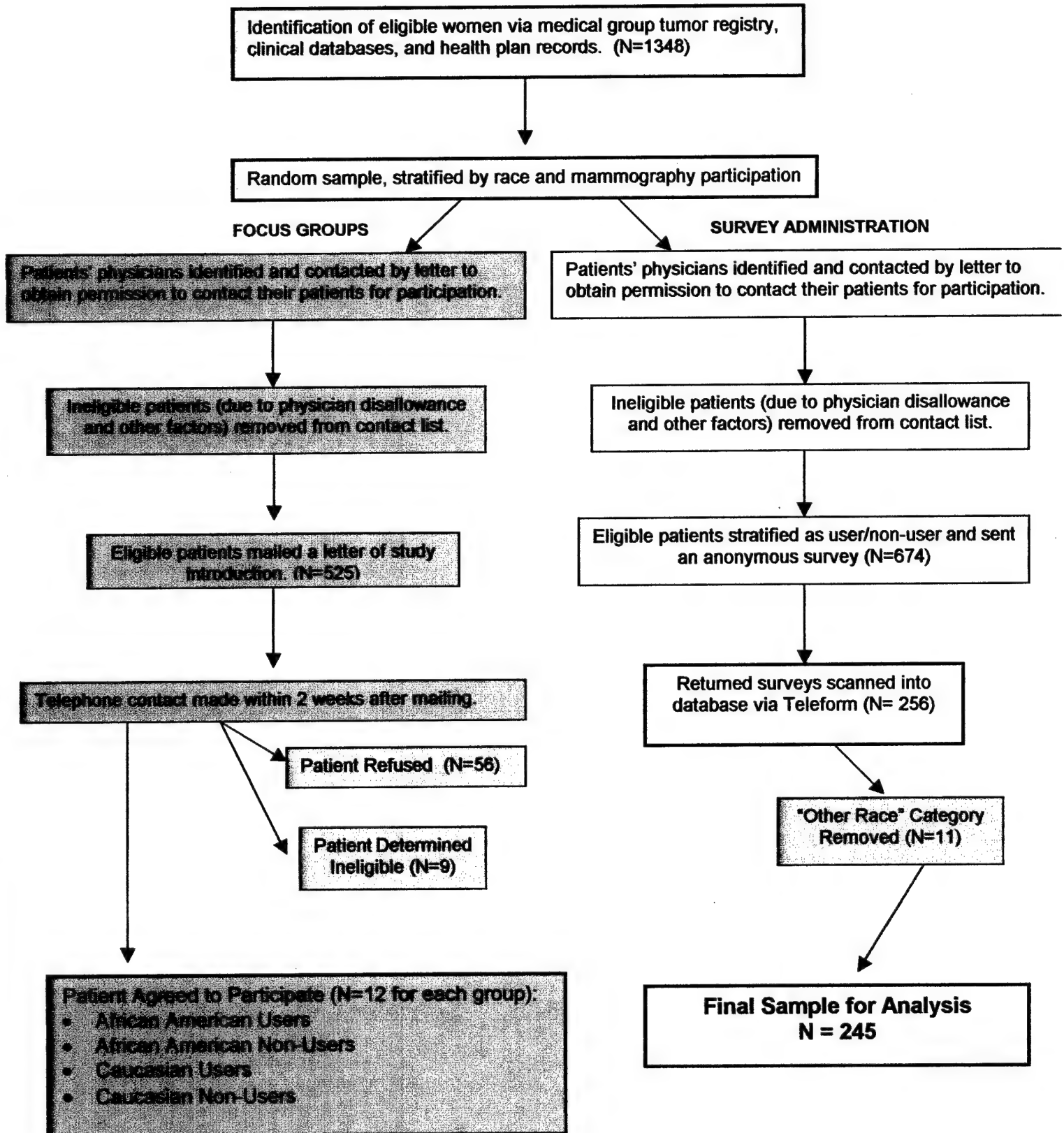
Christina Moon, MA - Project Coordinator

Appendix B:

**Enrollment
Process Chart**

APPENDIX B

Enrollment Process Chart

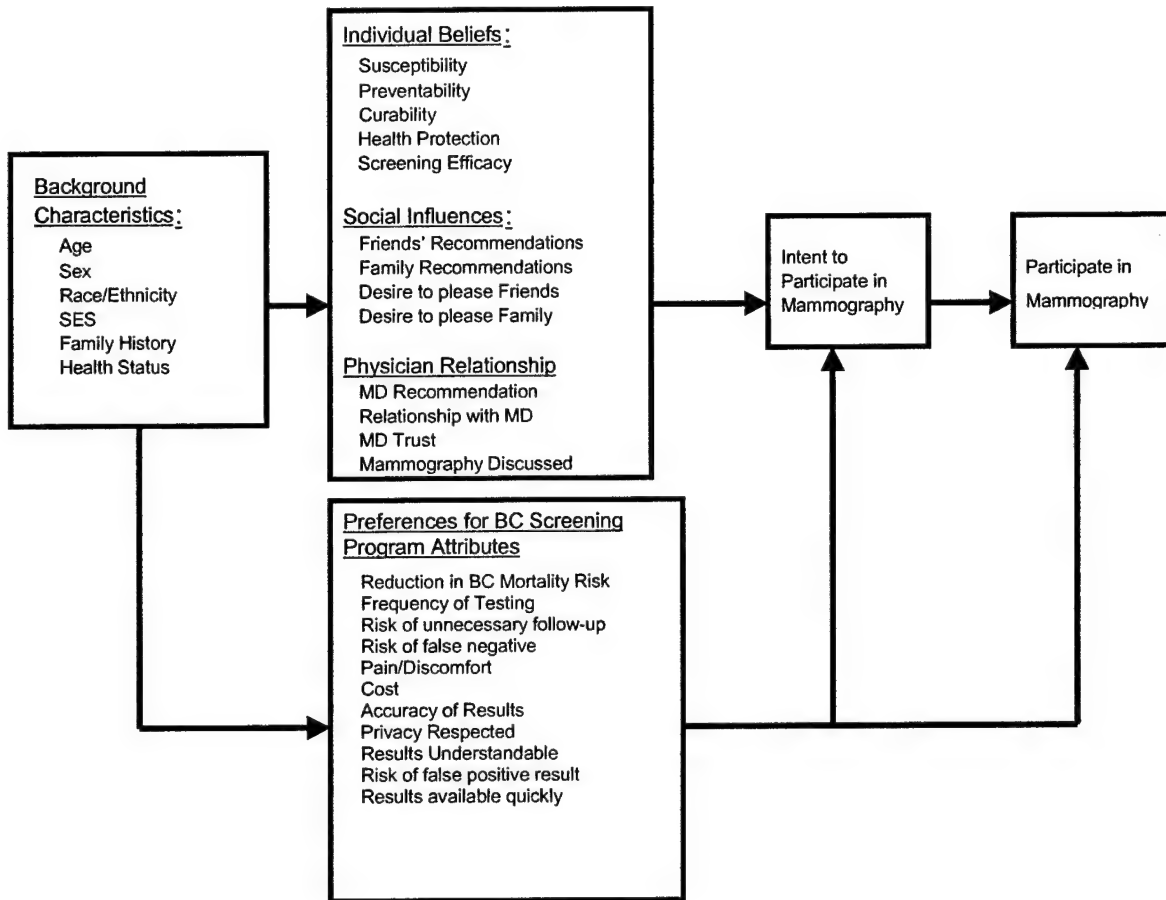


Appendix C:

Theoretical Model

Appendix C

Conceptual Model of Mammography Screening. (Adapted from Myers et al. 1994)



Appendix D:

**Focus Group
Guide**

Appendix D

Focus Group Guide

Focus Group Questions for Survey Development

Facilitator: _____

Assistants: _____

I. WARM-UP AND EXPLANATION (10 minutes)

A. Introduction

1. Good afternoon. My name is _____. I work with a company called SPEC Associates that conducts focus groups on behalf of organizations like Henry Ford Health System. This is _____ and _____. They will be the assistants today.
2. Thanks for coming. We appreciate you taking time out of your day to help us. As breast cancer survivors, you have a unique and exciting opportunity to share your thoughts and experiences so that we can learn about how to improve health care for women in the future.
3. Your presence and participation are important. Your thoughts and comments about getting a mammogram and a survey we are developing will be valuable in helping to provide future information on breast care issues. This focus group will be a two-part process: there will first be open-ended questions and then there will be a discussion and review of the survey you received when you signed in earlier.
4. We feel that everyone's opinions and comments are important. While there are a lot of questions to cover in a relatively short amount of time, we will try our best to hear from everyone. Please know that if we have to move on to a new topic it's not that we don't want to hear what you have to say, but that we have to keep moving in order to cover everything.

B. Purpose

1. What we are doing here today is called a focus group. It's a discussion to find out your opinions – like a survey.
2. I am interested in all of your ideas, comments and suggestions.
3. Each of you is very important and all of your comments – both positive and negative – are welcome.
4. There are no right or wrong answers.
5. Please speak up – even if you disagree with someone else here. It's important that I hear what each of you thinks.

C. Procedure

1. We will be audiotaping our discussion. Everything you say is important to us, and we want to make sure we don't miss any comments. Later we'll go through all of your

comments and use them to prepare a report on our discussion. However, all of your comments are confidential and will be used only for research purposes. Nothing you say will be connected to your name. Also, if any questions make you uncomfortable, feel free not to answer them.

2. You don't have to wait for me to call on you but please speak one at a time, so the tape recorder can pick up everything.
3. We have many topics to discuss so I may change the subject or move ahead. Please stop me if you want to add anything.

D. **Self-Introductions (Ice Breaker)**

1. Please tell us your name and your dream vacation.

II. GENERAL THOUGHTS ABOUT MAMMOGRAMS

BARRIERS

1. What do you think are the most important reasons why a woman who has survived breast cancer may choose **not** to receive a mammogram?
- 2a. Are there things that a doctor could tell a woman who has survived breast cancer that would make her **more likely** to get a mammogram?
- 2b. Are there things that a doctor could tell a woman who has survived breast cancer that would make her **less likely** to get a mammogram?
- 3a. What kinds of **good things** do women hear from family members or friends about **getting a mammogram** once they have been diagnosed with breast cancer?
- 3b. What kinds of **bad things** do women hear from family members or friends about **getting a mammogram** once they have been diagnosed with breast cancer?
4. What do you think are some fears breast cancer survivors have about getting a mammogram once they have been diagnosed with breast cancer?

PROBES:

What do you think would be some things that would keep a woman from getting a mammogram, even if she wanted to get one?

Do you think that some breast cancer survivors don't get a mammogram because they are **afraid to think about cancer**?

Do you think some breast cancer survivors don't get a mammogram because of the **discomfort** associated with a mammogram? the **embarrassment**? the **cost**? the **inconvenience**?

- 5a. Are there people in a breast cancer survivor's life who can **encourage** her to get a mammogram? Who are they and how do they do that?
- 5b. Are there people in a breast cancer survivor's life who can **discourage** her from getting a mammogram? Who are they and how do they do that?
6. To what extent do you think fear or mistrust of the medical establishment keep breast cancer survivors from getting a mammogram?

MOTIVATIONAL ITEMS

1. Are there things that you think would help motivate breast cancer survivors to get a mammogram?

PROBE: Are there other things that might motivate a breast cancer survivor to get a mammogram?

2. What do you think messages designed to encourage breast cancer survivors to get a mammogram should say?
3. Do most breast cancer survivors think that the results of a mammogram are reliable?

PROBE: On a scale of 1 to 10 (1 = not reliable, 10 = very reliable), how would you rate the reliability of mammogram results?

III. SURVEY

1. **Please look at the first page of the survey.**

Are the instructions on how to complete the survey clear?

If not, which words would you use to give instructions for completing the survey?

2. **Now, let's go to the first question.**

- a. Are any of questions 1 – 4 unclear to you?
If so, how would you ask these questions?
- b. How comfortable would you feel in answering questions 1-4?
- c. What makes you feel comfortable or uncomfortable about answering these questions?

3. Now, let's look at the section called "About Your Physician."

- a. Is the phrase "Think about the physician that you usually see about your breast care" clear to you?
If not, which word(s) would you use instead?
- b. Are any of the questions unclear?
If so, how would you ask these questions?

4. Now, let's look at the section called "Your Opinions."

- a. Is the meaning of the words "Your Opinions" clear to you?
If not, which word(s) would you use instead?
- b. Are the instructions on how to complete questions 7 and 8 clear to you?
If not, how would you give the instructions?
- c. Are questions 7 and 8 unclear?
If so, how would you ask these questions?
- d. How comfortable would you feel about answering questions 7 and 8?
- e. What makes you feel comfortable or uncomfortable about answering these questions?

5. Now, let's look at the section called "Your Preferences."

- a. Is the introduction to the "Your Preferences" section clear?
If not, which words would you use to introduce this section?
- b. Are the instructions on how to answer this section clear to you?
If not, how would you give the instructions?
- c. How comfortable would you feel about answering questions 9 and 10?
- d. What makes you feel comfortable or uncomfortable about answering these questions?
- e. What additional questions would you ask about opinions regarding mammograms?
- f. How hard would it be to fill out this section?
If you think it would be hard, what would make this question easier to fill out?
- g. If you think it would be easy, what makes it easy to fill out?

- h. Are there features that should be on or off the list?
If so, which ones?
- i. Let's look at the work "quickly" in *9f*. What does quickly mean to you?
- j. Let's look at "quickly" again in *9p*. What does quickly mean to you here?
- k. Are there any words or phrases in this section that are not clear to you?
If so, which words or phrases are not clear?

6. Let's turn now to "Your Background."

- a. How do you feel about surveys that include these types of questions?
- b. How comfortable or uncomfortable would you feel about answering these questions?
- c. What makes you feel comfortable or uncomfortable about answering these questions?
- d. Are there any questions that should be omitted?
If so, which ones? Why?

7. GENERAL THOUGHTS ABOUT THE SURVEY

- a. What makes you feel comfortable about completing the survey?
- b. Is there anything that would make you feel uncomfortable about completing the survey?
- c. How does the layout of the survey look to you?
- d. What would be some ways to improve the layout?
- e. How do you feel about the survey overall?
- f. If the survey were mailed to your home with a self-addressed postage-paid envelope, do you think you would complete and return the survey?

Appendix E:

**Focus Group
Summary**

Appendix E

Focus Group Summary

BARRIERS

BARRIERS	1. What do you think are the most important reasons why a woman who has survived breast cancer may choose <u>NOT</u> to receive a mammogram?	2a. Are there things that a doctor could tell a woman who has survived breast cancer that would make her <u>MORE LIKELY</u> to get a mammogram?	2b. Are there things that a doctor could tell a woman who has survived breast cancer that would make her <u>LESS LIKELY</u> to get a mammogram?
Caucasian – USERS	<ul style="list-style-type: none"> • Mam. not accurate in not showing cancer • False negatives • Mam misread by radiologist – wasn't brought to anyone's attention. • Didn't show cancer • Person who examine may not be good. • Have to be aggressive with the docs • Pain • Inaccuracy in reading • Type of cancer was difficult to see on mam • Depends who does the exam – some techs don't take careful reading • One lady had double mast., so didn't need mam anymore (per doc's orders) bc breast tissue was removed. Still worries about cancer coming back. 	<ul style="list-style-type: none"> • Cancer found early • Try to encourage • Encourage by telling you it would give you peace of mind • Tell people about latest research findings about accuracy of mams bc some docs not reassuring • More upfront about latest research re breast cancer – statistics, facts. • Doc keep checking on patients – need more reminders • Doc remind people about recurrences if they have had cancer 	<ul style="list-style-type: none"> • Doc says she didn't need bc of mast. – but she still worries about recurrence • Had info [?] it's gone – don't worry about it • Want someone that is concerned about their health
Caucasian - NON-USERS	<ul style="list-style-type: none"> • Afraid to come back – fear • Once you had it cured – wouldn't get again • Financial reasons • Think that it might not come back • If it comes back, it might be worse – couldn't deal with it again. 	<ul style="list-style-type: none"> • "I'll see you 2 weeks after your next mam" • letting them know that cancer can exist even though there are no lumps. • Schedule appt right after mam to see doc • Schedule regularly, routinely • Doc should just reiterate • Having info that can tell you mam was good • Pre-scheduled mams – problem with scheduling • Had bilateral – doesn't have to have mams anymore • Focus on early detection 	<ul style="list-style-type: none"> • Everything fine • Doc tells her she's fine, so he may give her false sense of security that everything is gone • Might say other health problems are more important
African-American – USERS	<ul style="list-style-type: none"> - could not think of a reason why women would not want to get a mam. - fear - heartless, painful, the way technicians handle your breast - if the breast is sore, and the person giving it is insensitive about the way they are handling it. - staff/technician rude, unfriendly, very insensitive - don't want to deal with it 	<ul style="list-style-type: none"> - cancer can come back - if a close family member has it, the breast cancer is more likely to come back - genetic 	<ul style="list-style-type: none"> - may not find cancer in mam., even if it is there. - not likely you'll get it again - if physician is a man, he may say it is not necessary

African-American - NON-USERS	1. What do you think are the most important reasons why a woman who has survived breast cancer may choose <u>NOT</u> to receive a mammogram? - could not think of a reason why women would not want to get a mam. - fear - discomfort - painful to them - rude or unfriendly staff/technician admin. mam.	2a. Are there things that a doctor could tell a woman who has survived breast cancer that would make her <u>MORE LIKELY</u> to get a mammogram? - prevention, early detection - cancer can come back	2b. Are there things that a doctor could tell a woman who has survived breast cancer that would make her <u>LESS LIKELY</u> to get a mammogram? - can't imagine anything that could be said
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	3a. What kinds of <u>GOOD THINGS</u> do women hear from family members or friends about getting a mammogram once they have been diagnosed with breast cancer?	3b. What kinds of <u>BAD THINGS</u> do women hear from family members or friends about getting a mammogram once they have been diagnosed with breast cancer?	4. What do you think are some fears breast cancer survivors have about getting a mammogram once they have been diagnosed with breast cancer?
Caucasian – USERS	<ul style="list-style-type: none"> • Family just assumes they'll go • Tell them the outcome • Family can be interested when told that she went. • One said most of her family assumes that she will take the initiative herself • Wear pink ribbon pens (breast cancer survivors helping others) • Don't need to encourage bc they assume you are doing the right thing and going. • Mostly they [fg members] encourage other people to go and get them bc they had had cancer. • Breast cancer survivors encourage other people more 	<ul style="list-style-type: none"> • Pain • Will it hurt • COST – money worries, insurance • Delay getting exam bc of insurance coverage • Will insurance cover cost of breast cancer? • Concerns about insurance programs changing 	<ul style="list-style-type: none"> • Fear of cancer coming back • Fear of radiation exposure over lifetime • Time off of work • Worry about not being able to work • Don't have time to take off work.
Caucasian - NON-USERS	<ul style="list-style-type: none"> • Lucky you got diagnosis • Remind her to take care of her health • Care for her health • Control of her health • Happy they survived – 1st cancer and happy things are going well • Expressing that they're happy and relieved that they got a mam. 	<ul style="list-style-type: none"> • Waiting for results, they bring this to the forefront. • Expressing own anxiety that they don't like mams • Talk about their own anxiety • Cost – can we afford this again 	<ul style="list-style-type: none"> • That it is back • Painful • Activating the post-traumatic experience • After diagnosis and mam – old feelings and fears come back about cancer
African-American – USERS	<ul style="list-style-type: none"> - early detection is key - continue to get them - it could save your life - reminders to get mam. 	<ul style="list-style-type: none"> - discomfort - someone died from it. That can be very discouraging. - It hurts 	<ul style="list-style-type: none"> - fear it will come back, go to other breast - too young - spread to other areas
African-American – NON-USERS	<ul style="list-style-type: none"> - You are going to be all right - Asking if it's time to get your mam. - survival - encouragement / force / threats - reassurance - advice - example (i.e., someone who has had cancer and repeat mam.s and are fine) - necessary - reminders to get mam. 	<ul style="list-style-type: none"> - discomfort - fear social life and love life will change 	<ul style="list-style-type: none"> - fear it will come back, go to other breast - too young - may not live long - fear of suffering - not attractive to a man - fear of treatment and treatment side effects

	PROBES: What do you think would be some things that would keep a woman from getting a mammogram, even if she wanted to get one?	Do you think that some breast cancer survivors don't get a mammogram because they are afraid to think about cancer?	Do you think that some breast cancer survivors don't get a mammogram because of the discomfort associated with a mammogram?
Caucasian – USERS	<ul style="list-style-type: none"> • Radiation exposure • Cost issue – very complicated to get a free mam (one was out of work and getting free mams but was too much red tape. Waited until she had a job again.) • Transportation problems • Babysitting problems • Just too busy – just keep putting it off • If feel nothing wrong, why go • Feel all right, don't feel sick • Just don't like the exam itself 	<ul style="list-style-type: none"> • Fear of coming back (most agree true) • Afraid of diving • Live for life 	<ul style="list-style-type: none"> • Pain delay getting, but still getting the test <p>The embarrassment? Don't feel embarrassed, older woman</p> <p>The cost? Cost – yes can be the issue.</p>
Caucasian - NON-USERS	<ul style="list-style-type: none"> • Not having ready access to clinic – scheduling appts in advance • Having to drive a long way • Other responsibilities, kids, elderly parents, work • Financial concerns • Too busy with everyday things, get caught up • Problems in scheduling one • Might not want to know results 	<ul style="list-style-type: none"> • Don't go, block out, don't have to deal with it. 	<ul style="list-style-type: none"> • Just an excuse • If don't have insurance, cost would be an issue • The responsibilities, too busy <p>The embarrassment? No, not an issue</p> <p>The cost? if don't have insurance, could would be an issue</p> <p>The inconvenience? The responsibilities, too busy.</p>
African-American – USERS	<ul style="list-style-type: none"> - Taking the time to get it scheduled - afraid - can't be on hold for hours - taking time off work - type of insurance / don't have insurance - if someone says that they are too young (age) 	<ul style="list-style-type: none"> - yes - denial, don't want to know - there may be scar tissue as AA keloid and mass may be misinterpreted 	<ul style="list-style-type: none"> - everyone expects discomfort (breast stays sore) <p>The embarrassment? No. What is embarrassing about it? Not big boobs?</p> <p>The cost? if don't have insurance, could would be an issue</p> <p>The inconvenience? The responsibilities, too busy.</p>
African-American – NON-USERS	<ul style="list-style-type: none"> - t.v. ads - don't want to know - scared of what they might find - maybe think she's too young - talking w/ people with cancer and watching media 	<ul style="list-style-type: none"> - Yes, just don't want to know 	<p>yes</p> <p>The embarrassment? Nothing embarrassing</p> <p>The cost? yes</p> <p>The inconvenience? Yes, but if you've been through it once, maybe not.</p>

	5a. Are there people in a breast cancer survivor's life who can ENCOURAGE her to get a mammogram? How do they do that?	5b. Are there people in a breast cancer survivor's life who can DISCOURAGE her from getting a mammogram? How do they do that?	6. To what extent do you think fear or mistrust of the medical establishment keep breast cancer survivors from getting a mammogram?
Caucasian - USERS	<ul style="list-style-type: none"> • Yes, but don't usually hear anything • Docs constantly reminding. Primary doc - keeps after her when she goes in for visit. • Family, daughter • Doc - just give them another referral • If didn't get one - she's sure family would be after her • Other cancer survivors (one said she never even talks about it with her friends) • PCPs (for example, if someone comes in for a cold, docs can ask about mams). • Some friends who have had bc but don't talk about it. 	<ul style="list-style-type: none"> • Wouldn't listen to anyone who would discourage them • Family member - denial of her having cancer (her husband) • Alternative cancer treatment, those type of publications may discourage people from going to a regular doc. • Articles/tv shows that try to encourage different types of treatment that may not be mainstream. 	<ul style="list-style-type: none"> • Sometimes • Even if cancer there?? • Cancer was hard to detect and they didn't see right away • Doc office had a lot of inaccuracies, misreads. • Clinic sent letter said it wasn't fine - misread reading • Docs don't know everything.
Caucasian - NON-USERS	<ul style="list-style-type: none"> • Children - concerned about moms. Want them to take care of themselves • Spouses - remind you, nag • Good friends - "I've had mine, have you had yours?" Could suggest getting mams together. • mom • Work environment - have mam screening weeks. Work can also encourage by offering to pay for them. 	<ul style="list-style-type: none"> • Anyone in your family who puts it down (find other excuses to tell you not to go) • Media - publicity that mam's cannot catch a lot of cancer cases. • "Do you have to?" • "Oh that again?" 	<ul style="list-style-type: none"> • Don't get discouraged, you should trust your doc • Their experience hasn't been a negative one • Fear - postpone mams • Once you've survived, if it wasn't a good experience. You might feel different • Maybe cultural issues would make other women feel different.
African-American - USERS	<ul style="list-style-type: none"> - Yes, family members, doctor, friends, children, siblings - family members who have survived cancer - focus / support groups - talking about cancer, bringing it out in the open - walkathons (e.g., Relays for Life) 	<ul style="list-style-type: none"> - caring friends not wanting you to go through changes as they've seen in the past. - Friends may say you really don't need that - Friends or family who saw the anguish you went through the first time may suggest herbs or alternative medicine. - Spouse may see what it cost us before and may say to just leave it in the Lord's hands. 	<ul style="list-style-type: none"> - mam. misread - if someone doesn't have a full understanding from the medical person as to options or x-ray, etc. (they don't take the time to explain), one may say why should I go. - not suggest alternative treatments - not found by mam. but by patient
African-American - NON-USERS	<ul style="list-style-type: none"> - Yes, family friends, when they tell you how much you mean to them - Children who ask questions showing concern - drive if no transportation - money - check exam schedule - make loving statements (e.g., love you, can't let anything happen to you) - show concern for wives - reiterate what can happen if don't get a mam. 	<ul style="list-style-type: none"> - negative friends and family giving bad advice - so-called friends who don't really care about you. 	<ul style="list-style-type: none"> - Whether or not they will be thorough in getting it all - Doctor or person there not having a personal touch or sensitive to them. - incorrect advice - question if they got it all the cancer - provider and/or staff's negative attitude - bad experience with treatment

MOTIVATIONAL ITEMS

	1. Are there things that you would think would help motivate breast cancer survivors to get a mammogram?	2. What do you think message designed to encourage breast cancer survivors to get a mammogram should say?	3. Do most breast cancer survivors think that the results of a mammogram are reliable?
Caucasian - USERS	<ul style="list-style-type: none"> When go to see doc – get mam right then. System of making so many appts don't book 6 mos. In advance, only book 3 mos in advance so you have to call back. Just a lot of calling to try to get an appt. Make the appt making simpler, less complicated. Want better access to getting mams Want better reminder system 	<ul style="list-style-type: none"> "I got mine – did you get yours" Point out it should be a part of routine care You said routinely do Remind them of how scared family was when you just went through this the 1st time. Try not to put them through that again. Encourage people to attend American Cancer Society Media-related messages. Breast cancer awareness month, PSAs, etc. Keep telling people to remind them 	<ul style="list-style-type: none"> Scale of 1-10 (10=very reliable): 8, 7, 6, 8, 9, 7, 8, 9 To some degree Human error ½ got diagnosed bc of mam [Most of the group thought they were reliable] more rare cancer was difficult to detect first thought they were fool-proof but they didn't fine. Now she knows they can make mistakes. Never had worried. Believed in mams strongly, when surgeon told her she had cancer she didn't believe him, said her mam was clear and they were wrong.
Caucasian - NON-USERS	<ul style="list-style-type: none"> Just receiving the slip of paper to go to radiology Get immediate results – get mam and results the same day Make an appt to see doc right after Knowledge that early detection is best See doc every 3-4 months Mailed reminder helpful. Doesn't let you forget. Have mams read the same day – very nice – don't have to wait for results (she goes to Karmonos breast cancer clinic – don't have the anxiety of waiting). 	<ul style="list-style-type: none"> Presence of micro calcifications can be an indicator of cancer. A lot of women don't know about this. 40% microcalcifications can cause cancer (these are not lumps) Magazines aren't telling women about this Messages to educate women more Mam now have ability to pick this up Mam's can pick up these things now Can have breast cancer and may not have a lump Pick up early enough – more available New advances going on in medical field People need to know that breast cancer is much more treatable today, and the survival rate is much better that it was...need to know about survival rates, etc. 	<ul style="list-style-type: none"> Scale 1-10: 10, 8, 10, 8, 9, 8 Does people who are breast cancer survivors get more care than the typical person going for annual check ups. Breast cancer survivors' mams might be more scrutinized. Mams may get better attention, don't have to wait and see

	1. Are there things that you would think would help motivate breast cancer survivors to get a mammogram?	2. What do you think message designed to encourage breast cancer survivors to get a mammogram should say?	3. Do most breast cancer survivors think that the results of a mammogram are reliable?
African-American - USERS	<ul style="list-style-type: none"> - diagnosed early, live longer - transportation - might not always find anything with a self exam - results of those survivors who had mams had it in the early stages - it took a second mam to detect the cancer 	<ul style="list-style-type: none"> - early detection - it could save your life - I survived breast cancer by a mammogram and early detection. - life depends on it, save your life 	<ul style="list-style-type: none"> - Yes, if found - They tell you mammograms are not 100% - 9, 8, 9, 9, 9, 7, 9, 9
African-American - NON-USERS	<ul style="list-style-type: none"> - insistent doctor - yes, they are alive now and can live on - not willing to leave husband to remarry, buy younger wife a new house 	<ul style="list-style-type: none"> - don't say anything about death/dying - it is time to get checked - your life depends on it - have several breast cancer survivors who have been alive 20-40 years after time to get your mam. - statistics that there are more survivors than those dying from the disease - not only kind of cancer - you're not a doctor 	<ul style="list-style-type: none"> - Most - 9, 9, 8, 10, 7, 10

Appendix F:

**Survey
Instrument**



Women's Health and Use of Health Services

INSTRUCTIONS: This survey asks you for your views about your health, your doctor, and getting a mammogram or breast cancer screening x-ray. Unless otherwise instructed, please fill in the circle that you feel best answers the question. You may use a pen or pencil to complete the survey. There are no right or wrong answers. We are interested in your opinions.

Please mail your completed survey in the enclosed self-addressed stamped envelope or mail to:
Center for Health Services Research, 1 Ford Place, Suite 3A, Detroit, MI 48202.

About Your Health...

1. In general, would you say your health is:
 - ☐ Excellent
 - ☐ Very good
 - ☐ Good
 - ☐ Fair
 - ☐ Poor
2. During the past month, have you often been bothered by feeling down, depressed, or hopeless?
☐ Yes ☐ No
3. During the past month, have you often been bothered by little interest or pleasure in doing things?
☐ Yes ☐ No

About Your Breast Care Doctor...

4. Think about the doctor that you see most often for your breast care. Thinking about that doctor, fill in only one circle for each statement.

	Always	Usually	Sometimes	Never
a. Does your doctor give you enough time to explain the reasons for your visit?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. When you ask questions, do you get answers that are understandable?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Does your physician take enough time to answer your questions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Does your physician ask you about how your family or living situation might affect your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Do you get as much medical information as you want from your physician?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. When you see your physician, do you have questions about your care that you want to discuss but do not?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Are you involved in decisions about your care as much as you want?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. Think about the doctor that you see most often for your breast care. Thinking about that doctor, mark only one circle for each statement.

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
a. I doubt that my doctor really cares about me as a person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. My doctor is usually considerate of my needs and puts them first.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I trust my doctor so much I always try to follow his/her advice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. If my doctor tells me something is so, then it must be true.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I trust my doctor's judgments about my medical care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. I sometimes don't trust my doctor's opinions and would like a second opinion.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. I feel my doctor does not do everything he/she should about my medical care.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. I trust my doctor to put my medical needs first when treating my medical problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. My doctor is a real expert in taking care of medical problems like mine.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. I trust my doctor to tell me if a mistake was made about my treatment.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. I sometimes worry that my doctor may not keep the information we discuss totally private.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Preferences...

6. Choosing whether or not to get a mammogram can be difficult. Refer to the list of mammogram features below and enter only **ONE LETTER** in each box.

- a. Of the features listed below, which **TWO** are the **MOST IMPORTANT** to you when choosing whether or not to get a mammogram?

 AND

- b. Of the features listed below, which **TWO** are the **LEAST IMPORTANT** to you when choosing whether or not to get a mammogram?

 AND

- c. Please indicate how important each of the following mammogram features are in choosing whether or not to get a mammogram.

	Very Important	Important	Not Very Important
A. Little pain or discomfort when getting the mammogram	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
B. Clinic staff respect my privacy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
C. My ability to avoid unnecessary follow-up testing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
D. Cost of the mammogram	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
E. Clinic staff are kind and friendly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
F. Waiting time at the mammogram clinic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
G. Mammogram test results are kept private	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
H. Mammogram test results are correct	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I. It is easy for me to schedule a mammogram appointment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
J. Ability to get a mammogram test that fits into my schedule	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
K. Little risk of side effects from the mammogram	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
L. The mammogram clinic is close to my home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
M. My mamogram test results are ready quickly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
N. Getting a mammogram does not take time away from work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
O. Getting a mammogram does not take time away from family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
P. I get reminder notices from my doctor's office to get a mammogram	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Q. Clinic staff include members of my racial and ethnic background	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your Background...

7. Your age: ☐ < 30 years
☐ 30 - 39 years
☐ 40 - 49 years
☐ 50 - 59 years
☐ 60 - 69 years
☐ 70 years or older
8. What was the last year of school you completed? ☐ Less than high school
☐ High school graduate or GED
☐ Some college / trade / tech school
☐ College graduate
☐ Post college graduate education
9. What is your current marital status? ☐ Married
☐ Living with a partner
☐ Divorced
☐ Separated
☐ Widowed
☐ Never married
10. Are you of Hispanic or Latin origin or background? ☐ Yes, Hispanic or Latino
☐ No, not Hispanic or Latino
11. Which of the following best describes your racial background? ☐ American Indian or Alaska Native
☐ Asian
☐ Black or African American
☐ Hispanic or Latino
☐ Native Hawaiian or Other Pacific Islander
☐ White or Caucasian
12. Are you currently employed at a job for pay? ☐ Yes
☐ No
13. In the past 12 months, have you had a mammogram? ☐ Yes
☐ No
14. In the next 12 months, do you intend on getting a mammogram? ☐ Yes
☐ No
15. Has a doctor ever told you that you have breast cancer?
☐ Yes. Please go to Question 16.
☐ No. STOP. Thank you very much for completing the survey.
Your answers are important to us. Please mail your completed survey in the enclosed self-addressed envelope.

16. Have you joined a support group for help with your breast cancer? ☐ Yes
☐ No

17. Has a doctor ever told you that you have a recurrence of breast cancer?

☐ Yes. STOP. Thank you very much for completing the survey.
 Your answers are important to us. Please mail your completed survey in the enclosed self-addressed envelope.

☐ No. Please go to Question 18.

Screening and You

18. This section is about mammography screening. Fill in only one circle for each statement.

	Strongly Disagree	Mildly Disagree	Mildly Agree	Strongly Agree
a. I believe the chance that I might develop breast cancer again is high.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. My close friends think that I should get a mammogram.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I think that compared to other persons my age, I am at lower risk for breast cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I want to do what members of my family think I should do about breast cancer screening.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I believe that mammography screening can help to protect my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. I want to do what my close friends think I should do about breast cancer screening.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. I believe that mammograms can help to find breast cancer recurrences early.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Members of my close family think that I should get a mammogram.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Other breast cancer survivors think that I should get a mammogram.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. I believe that when breast cancer recurrences are found early, they can be cured.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. My doctor thinks that I should get a mammogram each year.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l. I want to do what other breast cancer survivors think I should do about breast cancer screening.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m. I want to do what my doctor thinks I should do about breast cancer screening.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thank you very much for completing this survey.

Your answers are important to us.

Please mail your completed survey in the enclosed self-addressed envelope, or mail to:
 Center for Health Services Research, 1 Ford Place, Suite 3A, Detroit, MI 48202

Appendix G:

**Results Table
Comparison by
Race**

APPENDIX G
Results Tables: Analyses by Race (Caucasian/African American)

Table 1. Sociodemographic Characteristics and Health Status.

		Total (N=245) %	Caucasian (N=200) %	African American (N=45) %
Age	30-39 yrs	1	1	2
	40-49 yrs	15	14	18
	50-59 yrs	30	30	27
	60-69 yrs	22	23	22
	70+ yrs	31	32	31
Education	High School or Less	31	32	31
	Some College	30	29	33
	College Graduate or above	39	40	36
Marital Status *	Married or living w/ partner	60	64	40
Employment	Currently Employed	47	46	51
General Health	Excellent	12	12	11
	Very Good	35	39	18
	Good	36	33	52
	Fair	15	14	16
	Poor	2	2	2
Felt down, depressed, hopeless		28	26	35
Little pleasure, interest		22	19	23

* = p<.05 **=p<.01

Table 2A. Physician Interactions: Average Score

	Total	Caucasian (N=200)	African American (N=45)
Doctor gives enough time to explain reasons for visit	1.2±0.5	1.3±0.5	1.2±0.5
When asking questions, receive answers that are understandable	1.3±0.5	1.2±0.5	1.3 ± 0.5
Doctor takes enough time to answer questions	1.2±0.5	1.2±0.5	1.2±0.4
Doctor asks about how family or living situation might affect health	2.7±1.1	2.7±1.1	2.8±1.1
Receive as much medical information as wanted from doctor	1.5±0.7	1.5±0.6	1.5±0.7
When seeing doctor, have questions about care that want to discuss but do not	3.4±0.7	3.5±0.7	3.3±0.9
Involved in decision about care as much as want	1.5±0.6	1.4±0.6	1.6±0.8

1= Always
2= Usually
3= Sometimes
4= Never

Table 2B. Physician Interactions: Percent "Always/Usually"

	Total (N=245) %	Caucasian (N=200) %	African American (N=45) %
Doctor gives enough time to explain reasons for visit	97	97	95
When asking questions, receive answers that are understandable	98	98	98
Doctor takes enough time to answer questions	98	97	100
Doctor asks about how family or living situation might affect health	39	39	36
Receive as much medical information as wanted from doctor	93	93	91
When seeing doctor, have questions about care that want to discuss but do not	7	7	11
Involved in decision about care as much as want **	94	96	84

* = $p < .05$ ** = $p < .01$

Table 3A. Physician Trust: Average Score

	Total (N=245)	Caucasian (N=200)	African American (N=45)
I doubt my doctor really cares about me as a person	4.5±1.0	4.2±1.0	4.2±0.9
My doctor is usually considerate of my needs and puts them first	1.8±0.8	1.8 ±0.8	1.8±0.9
I trust my doctor so much that I always try to follow his/her advice	1.8±0.8	1.8±0.8	1.6±0.7
If my doctors tells me something is so, then it must be true	2.5±0.9	2.5±0.9	2.5±1.0
I trust my doctor's judgments about my medical care	1.7±0.6	1.7±0.6	1.6±0.5
I sometimes don't trust my doctor's opinions and would like a second one	3.6±1.0	3.6±1.0	3.5±1.0
I feel my doctor does not do everything he/she should about my medical care	4.2±0.9	4.2±0.9	4.0±1.1
I trust my doctor to put my medical needs above all other considerations when treating my medical problems	1.7±0.7	1.6±0.7	1.8±0.8
My doctor is a real expert in taking care of medical problems like mine	1.6±0.7	1.6±0.7	1.5±0.7
I trust my doctor to tell me if a mistake was made about my treatment	2.1±0.9	2.1±0.9	1.9±0.8
I sometimes worry that my doctor may not keep the information we discuss totally private *	4.2±1.0	4.3±0.9	3.8±1.2

* = p<.05 ** =p<.01

1= Strongly Agree

2= Agree

3 = Neither Agree/Disagree

4 = Disagree

5 = Strongly Disagree

Table 3B. Physician Trust: Percent "Strongly Agree/Agree"

	Total (N=245) %	Caucasian (N=200) %	African American (N=45) %
I doubt my doctor really cares about me as a person	7	8	5
My doctor is usually considerate of my needs and puts them first	86	86	88
I trust my doctor so much that I always try to follow his/her advice	86	85	93
If my doctors tells me something is so, then it must be true	51	51	48
I trust my doctor's judgments about my medical care	93	91	98
I sometimes don't trust my doctor's opinions and would like a second one	16	16	14
I feel my doctor does not do everything he/she should about my medical care	7	7	10
I trust my doctor to put my medical needs above all other considerations when treating my medical problems	94	93	95
My doctor is a real expert in taking care of medical problems like mine	87	86	90
I trust my doctor to tell me if a mistake was made about my treatment **	73	70	88
I sometimes worry that my doctor may not keep the information we discuss totally private **	5	3	14

* = p<.05 ** =p<.01

Table 4A. Attribute Ratings in Order of Importance by Race

	Total (N=245)	Caucasian (N=200)	African American (N=45)
Results are accurate **	1.1±0.2	1.0±0.2	1.1±0.4
Results are ready quickly	1.5±0.6	1.5±0.6	1.5±0.7
Clinic staff are kind, friendly	1.6±0.6	1.6±0.6	1.5±0.6
Ease of scheduling appt *	1.6±0.6	1.7±0.6	1.4±0.5
Clinic staff respects privacy	1.7±0.7	1.8±0.7	1.7±0.6
Receive reminder notices from doctor **	1.7±0.7	1.8±0.7	1.5±0.6
Avoid unnecessary follow-up testing	1.8±0.8	1.8±0.8	1.9±0.8
Little risk of side effects from exam	1.8±0.8	1.8±0.8	1.7±0.7
Results are kept private	1.8±0.7	1.9±0.7	1.7±0.6
Exam fits into schedule *	1.8±0.7	1.9±0.7	1.6±0.6
Waiting time at clinic	1.9±0.6	1.9±0.6	1.7±0.7
Clinic is close to home	2.1±0.7	2.1±0.7	2.2±0.8
Little pain or discomfort*	2.1±0.8	2.1±0.8	1.8±0.9
Exam doesn't take time away from work	2.4±0.7	2.5±0.7	2.3±0.7
Cost of mammogram	2.5±0.7	2.5±0.7	2.5±0.8
Exam doesn't take time away from family	2.6±0.6	2.6±0.6	2.5±0.6
Clinic staff include members of my racial/ethnic background **	2.8±0.5	2.8±0.5	2.5±0.7

* = p<.05 **=p<.01

1 = Very Important

2 = Important

3 = Not Very Important

Table 4B. Attributes Ranked as "Most Important" by Race

	Total (N=245) %	Caucasian (N=200) %	African American (N=45) %
Results are accurate *	61	65	47
Results are ready quickly	24	26	13
Little pain or discomfort *	16	13	27
Little risk of side effects from exam	11	11	11
Avoid unnecessary follow-up testing	10	10	9
Clinic staff are kind, friendly	8	7	13
Receive reminder notices from doctor	8	7	11
Ease of scheduling appt	7	7	7
Exam fits into schedule	5	6	2
Results are kept private	4	3	7
Clinic is close to home	4	4	4
Waiting time at clinic	3	4	2
Clinic staff respects privacy	3	4	0
Cost of mammogram	3	4	0
Exam doesn't take time away from work *	0	0	2
Exam doesn't take time away from family	0	1	0
Clinic staff include members of my racial/ethnic background	0	0	0

* = p<.05 **=p<.01

Table 4C. Attributes Ranked as "Least Important" by Race

	Total (N=245) %	Caucasian (N=200) %	African American (N=45) %
Clinic staff include members of my racial/ethnic background	53	56	42
Cost of mammogram	22	21	27
Exam doesn't take time away from work	20	22	16
Exam doesn't take time away from family	17	18	13
Clinic is close to home	11	12	11
Little pain or discomfort	9	9	7
Receive reminder notices from doctor	7	8	2
Waiting time at clinic	7	6	11
Results are kept private	5	6	0
Exam fits into schedule	4	5	4
Results are ready quickly *	3	2	9
Results are accurate	2	1	4
Little risk of side effects from exam	3	3	2
Avoid unnecessary follow-up testing	1	1	2
Clinic staff are kind, friendly *	0	0	2
Clinic staff respects privacy	0	1	0
Ease of scheduling appt	0	0	0

* = p<.05 **=p<.01

Table 4D. Attributes Rated as "Very Important/Important" by Race

	Total (N=245) %	Caucasian (N=200) %	African American (N=45) %
Results are accurate	100	100	100
Ease of scheduling appt	96	95	100
Clinic staff are kind, friendly	95	95	98
Results are ready quickly	94	94	91
Clinic staff respects privacy	88	87	93
Exam fits into schedule	85	83	93
Waiting time at clinic	85	84	91
Receive reminder notices from doctor *	83	80	93
Results are kept private	80	78	90
Little risk of side effects from exam	81	79	86
Avoid unnecessary follow-up testing	79	79	73
Clinic is close to home	67	68	63
Little pain or discomfort	63	61	67
Exam doesn't take time away from work	44	41	56
Cost of mammogram	39	40	33
Exam doesn't take time away from family	36	34	45
Clinic staff include members of my racial/ethnic background **	15	10	36

* = $p < .05$ ** = $p < .01$

Table 5. Breast Cancer & Mammogram Status.

	Total (N=245) %	Caucasian (N=200) %	African American (N=45) %
Intend on getting mammogram in next 12 months	95	96	91
Joined a support group for help with breast cancer	14	15	7
Doctor ever told you that you have a recurrence of breast cancer	7	7	7

Table 6A. Social Support and Risk Perception: Average Score

	Total (N=245)	Caucasian (N=200)	African American (N=45)
Chance of developing breast cancer again is high **	2.6±0.9	2.8±0.9	2.0±1.0
Close friends think I should get a mam *	3.2±1.1	3.3±1.0	2.8±1.2
Compared to others my age, I am at lower risk for breast cancer	1.8±0.9	1.8±0.8	2.0±1.1
Want to do what members of my family think I should do about breast cancer screening	2.9±1.1	2.9±1.1	2.8±1.2
Believe mam screening can help to protect health	3.7±0.7	3.8±0.6	3.5±1.1
Want to do what close friends think I should do about breast cancer screening	2.5±1.1	2.6±1.1	2.3±1.2
Believe mams can help find breast cancer recurrences early	3.7±0.7	3.8±0.6	3.4±1.1
Members of close family think I should get a mam	3.5±0.9	3.5±0.9	3.5±0.9
Other breast cancer survivors think I should get a mam	3.4±1.0	3.4±0.9	3.3±1.1
Believe when breast cancer recurrences are found early, they can be cured	3.5±0.8	3.5±0.7	3.5±1.0
My doc thinks I should get a mam each year	3.9±0.5	3.9±0.4	3.8±0.8
Want to do what other breast cancer survivors think I should do about breast cancer screening	2.9±1.0	3.0±1.0	2.7±1.3
Want to do what my doc thinks I should do about breast cancer screening	3.8±0.5	3.9±0.5	3.7±0.8

*= $p<.05$ **= $p<.01$

1= Strongly Disagree

2= Disagree

3= Neither Agree/Disagree

4= Agree

5= Strongly Agree

Table 6B. Social Support and Risk Perception: Percent "Strongly Agree/Agree"

	Total (N=245) %	Caucasian (N=200) %	African American (N=45) %
Chance of developing breast cancer again is high **	60	67	30
Close friends think I should get a mam	79	81	68
Compared to others my age, I am at lower risk for breast cancer	22	20	32
Want to do what members of my family think I should do about breast cancer screening	66	67	62
Believe mam screening can help to protect health	94	96	86
Want to do what close friends think I should do about breast cancer screening	55	57	47
Believe mams can help find breast cancer recurrences early	93	95	83
Members of close family think I should get a mam	88	88	86
Other breast cancer survivors think I should get a mam	85	87	78
Believe when breast cancer recurrences are found early, they can be cured	91	91	88
My doc thinks I should get a mam each year	97	98	93
Want to do what other breast cancer survivors think I should do about breast cancer screening	69	71	63
Want to do what my doc thinks I should do about breast cancer screening	97	98	92

*=p<.05 **=p<.01

Appendix H:

**Results Table
Comparison by
Use**

APPENDIX H
Results Tables: Analyses by Utilization (User/Non-User)

Table 1. Sociodemographic Characteristics and Health Status.

		Non-User (N=22) %	User (N=223) %
Age	30-39 yrs	0	1
	40-49 yrs	14	15
	50-59 yrs	27	30
	60-69 yrs	23	23
	70+ yrs	36	31
Education	High School or Less	34	31
	Some College	24	30
	College Graduate or above	43	38
Marital Status	Married or living w/ partner	55	60
Employment	Currently Employed	59	45
General Health	Excellent	10	12
	Very Good	45	34
	Good	45	36
	Fair	0	16
	Poor	0	2
Felt down, depressed, hopeless		26	28
Little pleasure, interest		25	19

* = p<.05 **=p<.01

Table 2A. Physician Interactions: Average Score

	Non-User (N=22)	User (N=223)
Doctor gives enough time to explain reasons for visit	1.5±0.2	1.3±0.5
When asking questions, receive answers that are understandable	1.3±0.6	1.3±0.5
Doctor takes enough time to answer questions	1.1±0.3	1.2±0.5
Doctor asks about how family or living situation might affect health	2.4±1.2	2.8±1.1
Receive as much medical information as wanted from doctor	1.5±0.6	1.5±0.7
When seeing doctor, have questions about care that want to discuss but do not	3.3±0.7	3.5±0.7
Involved in decision about care as much as want	1.6±0.7	1.5±0.6

1= Always
2= Usually
3= Sometimes
4= Never

Table 2B. Physician Interactions: Percent "Always/Usually"

	Non-User (N=22) %	User (N=223) %
Doctor gives enough time to explain reasons for visit	95	97
When asking questions, receive answers that are understandable *	91	98
Doctor takes enough time to answer questions	100	98
Doctor asks about how family or living situation might affect health	52	37
Receive as much medical information as wanted from doctor	95	92
When seeing doctor, have questions about care that want to discuss but do not	5	8
Involved in decision about care as much as want	86	95

* = $p < .05$ ** = $p < .01$

Table 3A. Physician Trust: Average Score

	Non-User (N=22)	User (N=223)
I doubt my doctor really cares about me as a person	4.1±0.7	4.5±1.0
My doctor is usually considerate of my needs and puts them first	1.8±0.7	1.8±0.8
I trust my doctor so much that I always try to follow his/her advice	1.7±0.6	1.8±0.8
If my doctors tells me something is so, then it must be true	2.2±0.8	2.5±0.9
I trust my doctor's judgments about my medical care	1.6±0.6	1.7±0.6
I sometimes don't trust my doctor's opinions and would like a second one	3.7±0.8	3.6±1.0
I feel my doctor does not do everything he/she should about my medical care	4.5±0.6	4.2±1.0
I trust my doctor to put my medical needs above all other considerations when treating my medical problems	1.7±0.6	1.7±0.7
My doctor is a real expert in taking care of medical problems like mine	1.9±0.8	1.6±0.7
I trust my doctor to tell me if a mistake was made about my treatment	1.9±0.8	2.1±0.9
I sometimes worry that my doctor may not keep the information we discuss totally private	4.3±0.7	4.5±1.0

* = p<.05 ** =p<.01

1= Strongly Agree

2= Agree

3 = Neither Agree/Disagree

4 = Disagree

5 = Strongly Disagree

Table 3B. Physician Trust: Percent "Strongly Agree/Agree"

	Non-User (N=22) %	User (N=223) %
I doubt my doctor really cares about me as a person	0	8
My doctor is usually considerate of my needs and puts them first	86	86
I trust my doctor so much that I always try to follow his/her advice	95	86
If my doctors tells me something is so, then it must be true	64	49
I trust my doctor's judgments about my medical care	95	92
I sometimes don't trust my doctor's opinions and would like a second one	5	17
I feel my doctor does not do everything he/she should about my medical care	0	8
I trust my doctor to put my medical needs above all other considerations when treating my medical problems	95	94
My doctor is a real expert in taking care of medical problems like mine	77	88
I trust my doctor to tell me if a mistake was made about my treatment	82	72
I sometimes worry that my doctor may not keep the information we discuss totally private	0	5

* = p<.05 ** =p<.01

Table 4A. Attribute Ratings in Order of Importance by Mammogram Utilization

	Non-User (N=22)	User (N=223)
Results are accurate	1.0±0.2	1.1±0.2
Results are ready quickly	1.6±0.6	1.5±0.6
Clinic staff are kind, friendly	1.7±0.7	1.6±0.6
Ease of scheduling appt	1.7±0.6	1.6±0.6
Clinic staff respects privacy	1.7±0.7	1.7±0.6
Receive reminder notices from doctor *	2.1±0.9	1.7±0.7
Avoid unnecessary follow-up testing	2.0±0.8	1.8±0.7
Little risk of side effects from exam	1.7±0.7	1.8±0.8
Waiting time at clinic	2.0±0.6	1.9±0.6
Results are kept private	1.9±0.7	1.8±0.7
Exam fits into schedule	1.7±0.6	1.8±0.7
Clinic is close to home	2.0±0.7	2.1±0.7
Little pain or discomfort	1.9±0.8	2.1±0.8
Cost of mammogram	2.6±0.5	2.5±0.7
Exam doesn't take time away from work	2.4±0.7	2.4±0.7
Exam doesn't take time away from family	2.5±0.7	2.6±0.6
Clinic staff include members of my racial/ethnic background	2.9±0.5	2.8±0.5

* = p<.05 **=p<.01

1 = Very Important

2 = Important

3 = Not Very Important

Table 4B. Attributes Ranked as "Most Important" by Mammogram Utilization

	Non-User (N=22) %	User (N=223) %
Results are accurate	59	61
Little pain or discomfort	14	16
Results are ready quickly	18	24
Little risk of side effects from exam	18	10
Clinic staff are kind, friendly	9	8
Avoid unnecessary follow-up testing	0	11
Receive reminder notices from doctor	0	9
Ease of scheduling appt	5	7
Results are kept private	9	3
Exam fits into schedule	14	4
Clinic is close to home	9	4
Waiting time at clinic	0	4
Clinic staff respects privacy	9	2
Cost of mammogram	0	3
Exam doesn't take time away from work	0	0
Exam doesn't take time away from family	0	0
Clinic staff include members of my racial/ethnic background	0	0

* = $p < .05$ ** = $p < .01$

Table 4C. Attributes Ranked as "Least Important" by Mammogram Utilization

	Non-User (N=22) %	User (N=223) %
Clinic staff include members of my racial/ethnic background	55	53
Cost of mammogram	18	22
Exam doesn't take time away from work	14	21
Exam doesn't take time away from family	27	16
Clinic is close to home	9	12
Waiting time at clinic	0	8
Little pain or discomfort	0	9
Results are ready quickly	5	3
Receive reminder notices from doctor	18	6
Exam fits into schedule	9	4
Results are kept private	0	5
Results are accurate	0	2
Little risk of side effects from exam	5	3
Avoid unnecessary follow-up testing	0	1
Clinic staff are kind, friendly	0	0
Clinic staff respects privacy	0	0
Ease of scheduling appt	0	0

* = p<.05 **=p<.01

Table 4D. Attributes Rated as "Very Important/Important" by Race

	Total (N=245) %	Non-User (N=22) %	User (N=223) %
Results are accurate	100	100	100
Ease of scheduling appt	96	95	96
Clinic staff are kind, friendly	95	90	96
Results are ready quickly	94	95	93
Clinic staff respects privacy	88	86	89
Exam fits into schedule	85	90	84
Waiting time at clinic	85	81	86
Receive reminder notices from doctor **	83	57	85
Results are kept private	80	81	80
Little risk of side effects from exam	81	86	80
Avoid unnecessary follow-up testing	79	67	80
Clinic is close to home	67	76	66
Little pain or discomfort	63	75	61
Exam doesn't take time away from work	44	48	44
Cost of mammogram	39	37	39
Exam doesn't take time away from family	36	38	36
Clinic staff include members of my racial/ethnic background **	15	10	15

* = $p < .05$ ** = $p < .01$

Table 5. Breast Cancer & Mammogram Status.

	Non-User (N=22) %	User (N=223) %
Intend on getting mammogram in next 12 months *	86	96
Joined a support group for help with breast cancer	10	14
Doctor ever told you that you have a recurrence of breast cancer	10	7

* = $p < .05$ ** = $p < .01$

Table 6A. Social Support and Risk Perception: Average Score

	Non-User (N=22)	User (N=223)
Chance of developing breast cancer again is high	2.7±0.7	2.6±1.0
Close friends think I should get a mam	3.2±1.2	3.2±1.1
Compared to others my age, I am at lower risk for breast cancer	2.1±1.2	1.8±0.9
Want to do what members of my family think I should do about breast cancer screening	3.2±1.1	2.9±1.1
Believe mam screening can help to protect health	3.8±0.4	3.7±0.7
Want to do what close friends think I should do about breast cancer screening	2.8±1.1	2.5±1.1
Believe mams can help find breast cancer recurrences early	3.9±0.4	3.7±0.8
Members of close family think I should get a mam	3.5±0.69	3.5±0.9
Other breast cancer survivors think I should get a mam	3.3±0.9	3.4±1.0
Believe when breast cancer recurrences are found early, they can be cured	3.8±0.4	3.5±0.8
My doc thinks I should get a mam each year	3.8±0.5	3.9±0.5
Want to do what other breast cancer survivors think I should do about breast cancer screening	3.0±0.9	2.9±1.1
Want to do what my doc thinks I should do about breast cancer screening	3.7±0.6	3.8±0.5

*= $p<.05$ **= $p<.01$

1= Strongly Disagree

2= Disagree

3= Neither Agree/Disagree

4= Agree

5= Strongly Agree

Table 6B. Social Support and Risk Perception: Percent "Strongly Agree/Agree"

	Non-User (N=22) %	User (N=223) %
Chance of developing breast cancer again is high	58	60
Close friends think I should get a mam	71	79
Compared to others my age, I am at lower risk for breast cancer	35	21
Want to do what members of my family think I should do about breast cancer screening	67	66
Believe mam screening can help to protect health	100	94
Want to do what close friends think I should do about breast cancer screening	57	55
Believe mams can help find breast cancer recurrences early	100	92
Members of close family think I should get a mam	93	88
Other breast cancer survivors think I should get a mam	86	85
Believe when breast cancer recurrences are found early, they can be cured	100	90
My doc thinks I should get a mam each year	95	97
Want to do what other breast cancer survivors think I should do about breast cancer screening	76	69
Want to do what my doc thinks I should do about breast cancer screening	95	97

*= $p < .05$ **= $p < .01$

Appendix I:

**Abstract to
Era of Hope**

Appendix I
Abstract for Poster Presentation to Era of Hope Conference 2003

Era of Hope 2002 Department of Defense Breast Cancer Research Program Meeting

Background: Despite general consensus that breast cancer survivors should undergo annual mammography, findings indicate over 1 in 7 women fail to receive a mammogram within two years of breast cancer treatment, and that African Americans are almost half as likely to participate in mammography screening as Caucasians.

Objectives: To develop and pilot test a survey instrument to understand what factors influence a breast cancer survivor's decision to receive mammography and whether differences exist in these factors by patient race.

Methods: Using information from the literature and four focus groups (two among African American and two among Caucasian breast cancer survivors), we are developing a mailed patient survey. In the final phase of the study, the survey is being mailed to a random sample of 100 African American and Caucasian breast cancer survivors. Using logistic regression, results from the survey will be analyzed to identify the beliefs, social influences, and preferences for mammography screening attributes, controlling for patient socio-demographic and other background characteristics (e.g., family history and comorbidities), which are related to mammography participation.

Results: Results from the literature review have led to the development of a conceptual model of mammography use among breast cancer survivors. This model, which draws heavily upon both the health behavior and economic literature, reflects our theorized importance of not only patient beliefs and social influences, but also their preferences for different mammography screening program attributes such as the accuracy of the test, the privacy of results, or the pain associated with testing. Definitive results from the focus groups and preliminary results from the mailed survey will be available at the time of presentation.

Appendix J:

**Abstract to
SMDM**

APPENDIX J
Abstract Submitted to Society for Medical Decision Making

RACIAL DIFFERENCES IN THE STATED IMPORTANCE OF MAMMOGRAPHY CARE FEATURES AFTER TREATMENT FOR BREAST CANCER

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Purpose: Using data from a pilot study of racial differences in mammography use following breast cancer treatment, we describe stated importance of care attributes considered in deciding to receive mammography screening, and evaluate differences in stated importance by race.

Methods: A cohort of breast cancer survivors aged 40+ who received curative treatment between 1995 and 2000 in an integrated health system were identified. We randomly selected cohort members to participate in 4 focus groups (N=14 Cauc and N=15 AA) to identify care attributes women consider when deciding whether to use mammography. These results were used to develop a mailed survey that included a 'rank then rate' exercise pertaining to the importance of 17 factors when deciding whether or not to use mammography screening. The survey was returned by 245 women (39% response rate). Wilcoxon Rank Sum (ranking) and Chi square tests (rating) were used to evaluate differences ($p < 0.10$) in importance by race.

Results: In the ranking exercise, "Test results are correct" was most likely to be listed by both AA and Cauc women (47 and 65%, respectively) as 1 of the 2 most important considerations, followed by "test results available quickly" (26%) and then "little pain/discomfort" (13%) for Cauc women and "little pain/discomfort" (27%) and then "test results available quickly" (13%) and "kind and friendly staff" (13%) for AA women. The rating of importance differed by race for only 4 care attributes: Compared to Cauc women, AA women were more likely to state that "reminders for care" (80 vs. 93%), "privacy of results" (78 vs. 90%), "need to take time from work" (41 vs. 56%), and "race of clinic staff" (10 vs. 36%) were important considerations.

Conclusions: Both AA and Cauc respondents valued accurate and rapid test results and the pain/discomfort associated with testing. Opportunities to improve adherence may exist by improving test accuracy, implementing procedures to assure quick results reporting, and minimizing test discomfort. Attention to interpersonal aspects of mammography screening may afford opportunities to reduce racial differences in adherence.